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What motivates or influences nurses to become hospice nurses?

Teresa Ann Simpson
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WHAT MOTIVATES OR INFLUENCES NURSES
TO BECOME HOSPICE NURSES?

A Thesis
Presented to
The Faculty of the School of Nursing
San Jose State University

In Partial Fulfillment
of the Requirements for the Degree
Master of Science

by
Teresa Ann Simpson
December, 1997

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ABSTRACT

WHAT MOTIVATES OR INFLUENCES NURSES TO BECOME HOSPICE NURSES?

By Teresa Ann Simpson

This thesis examined experiences and beliefs of hospice nurses in order to identify what motivated or influenced them to choose this specialty field. Flyers were distributed and posted in local hospices seeking volunteer informants who were currently working as registered nurses. Hospice nurses were pre-screened for eligibility and five subjects were purposively selected to represent an experience rich informant pool. Nurses were interviewed utilizing a semi-structured interview guide developed by the researcher. Interviews were tape recorded, transcribed and analyzed according to phenomenologic research methods.

Thirteen primary and fifteen secondary themes were identified from the interviews. Exemplars were used to describe the lived experience of the hospice nurse and what these nurses viewed as the essence of their work, what made this type of nursing special, and common and or unique life experiences or values among nurses that choose hospice nursing. Suggestions were recommended for future research.

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To my husband, Paul,
and to my daughters Katie and Heidi,
who have always loved, supported,
and encouraged me in my work,
which is "His" work.

You make life worth living
and are confirmation
that the most important things in this
lifetime and throughout eternity
are our relationships with those whom we love.

Thank you.

I Love You.

"Verily I say unto you,
Inasmuch as ye have done it
unto one of the least of these my brethren,
ye have done it unto me"
(St. Matthew, Chapter 25, Verse 40, p. 1233).

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Chapter 1

INTRODUCTION

Background

Hospice is a philosophy of care that guides support for persons and their families during the last phases of an incurable illness. Hospice care is palliative in nature, with the focus of treatment shifting from the cure to the care modality. Hospice nursing includes the realms of the physical, social, spiritual, and emotional aspects of patient care during the last stages of a terminal illness, throughout the dying process, and into the bereavement phase following death. Hospice care may take place in a specialty unit of a hospital, in a free standing community based hospice, in a skilled nursing facility, or in a patient's home. The "unit of care" in hospice is the patient and their family, with care available 24 hours a day, seven days a week, 365 days a year.

Hospice care is holistic, multifaceted, and all encompassing by nature. When hospice nursing is viewed from the perspective of an outsider looking in, it can appear overwhelming and depressing. Outsiders may perceive death to be the fundamental focus of hospice nursing, while those who work in this specialty care area view life and the quality of each remaining day as being the heart of their care.

Problem

Hospice nurses care for the terminally ill on a daily basis, knowing all of their patients will die. "The death of a patient is perceived as a humiliation by the average physician in American culture; to the nursing staff in an acute-care hospital, it feels like a personal defeat" (Campbell, 1986, p. 336). However, hospice nurses have learned to change the focus of their care which they learned in nursing school, from curing the disease to caring for the patient and the family in a holistic manner until death occurs. The focus of the hospice nurses' practice becomes the antithesis of what they were taught in school and is often contrary to the practices of their colleagues working in the acute care hospitals and clinics. Hospice nurses shun the idea of fighting to keep someone alive with the aid of expensive medical technology and highly specialized knowledge, if, once the battle is won, there is no quality of life for the patient.

A referral to hospice may be perceived by the hospital and clinic based staff as giving up on the patient and giving in to the disease. The acute care team may feel like they have lost a war and must now admit defeat, because their technology and specialized knowledge have failed to cure the patient and prolong life. For the hospice nurse and patient, the caregiving battle is one of quantity of

life verses quality of life. Many patients and their families do not embrace the medical community's various attempts to prolong their lives because the cure is often worse than the disease itself. Hospice nurses and their patients accept death. Hospice nurses often welcome death and may celebrate death when it occurs in the patient's home, according to the patient's wishes, without the aid of high-tech interventions.

Hospice patients, their families, and the hospice staff know that death is inevitable, with the ultimate goal being a dignified, pain free death. While acute care nurses may shy away from talking about death with a patient or a family member, hospice nurses talk about death frequently and welcome the opportunity to facilitate open family communication on the subject. It is the responsibility of the hospice interdisciplinary team to assist the patient and family to attain a degree of mental and spiritual preparation for death that is satisfactory to them, ensuring quality of life and a quality death experience.

Purpose of Study

Hospice nurses knowingly enter a specialty care area in which their patients will not get better. With the realization that each of their patients will eventually die, why do hospice nurses choose this type of nursing?

The purpose of this study was to describe the lived

experience of the hospice nurse using a phenomenological research approach. This research sought to describe hospice nursing from the perspective of those who work in this specialty care area in order to explore what motivated or influenced these nurses to specialize in this type of nursing care, what makes hospice nursing special to them, and what they consider to be the essence of their work.

Research Questions

The main research question for this study was: What is the lived experience of the hospice nurse? Additional sensitizing questions that guided this research were: What makes hospice nursing special to those who choose this specialty care area? What do hospice nurses view as the essence of their practice? What are the common and/or unique life experiences, perspectives, or values among nurses that choose hospice nursing?

Summary

Hospice is not a place, but a holistic philosophy of care that guides support for the terminally ill patient and his/her family throughout the dying process. Hospice nurses care for dying patients on a daily basis utilizing palliative interventions, seeking to ensure quality, not necessarily quantity of life. This research sought to describe the lived experience of the hospice nurse through identifying common themes and unique values or life

perspectives, and focused on the motivational factors of these professional caregivers in order to understand what influenced them to enter hospice nursing.

Chapter 2

CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

Introduction

Both hospice and oncology nurses work with patients who have incurable diseases and are dying, however their orientation to care and goals of treatment differ dramatically. Some research suggests these two types of nurses are distinctively different in terms of their personality traits, rates of burnout, spiritual nursing practices, and motivational factors. The oncology nurses have a strong professional nursing society and much research has been devoted to the study of the oncology nurse and his/her practice. Very limited nursing research has been done on the hospice nurse and no phenomenological research has been done to describe the lived experience of the hospice nurse.

Definition of a Hospice Nurse

Of the studies analyzed for this literature review, few of them differentiate between oncology and hospice nursing in the care of patients with cancer. Hospice and oncology nursing are often grouped together for the purpose of research since both practices primarily deal with cancer patients and their eventual death from the disease. However, there is a distinct difference in the orientation of care and treatment goals between these two categories of

nurses who deal with the terminally ill. Hospital and clinic based oncology nursing approaches the patient from a cure mentality, with a plan of care that is medically directed toward curing the disease and extending the patient's life. Hospice nurses orient their practice towards the care model of holistic nursing. Hospice nurses focus on quality of life with a plan of care that is abundantly weighted with nursing interventions to achieve palliation of symptoms as the ultimate goal.

For the purpose of this study, the researcher makes the above distinction to clarify the differences between oncology nurses and hospice nurses. The literature also supports this distinction.

Literature Review

The following discussion addresses eight key areas of differences and similarities between hospice and oncology nurses which are: (a) traits, (b) rate of burnout, (c) life cycle, (d) view of work, (e) "being there," (f) intrinsic and extrinsic motivation, (g) job satisfaction, and (h) the lived experience of the oncology nurse.

Traits

Amenta (1984) compared the traits of hospice nurses with the traits of those who work in traditional settings. Amenta found hospice nurses to be significantly more assertive, imaginative, forthright, free-thinking, and

independent than their colleagues who scored lower than the norms on a battery of five standardized tests. Nurses who worked in traditional settings exhibited a practical, no-nonsense approach to life when compared to the norm and to hospice nurses. These traditional nurses were more concrete, more task-oriented than theoretical, and were more concerned with negotiating the present than dreaming of the future. In many instances, Amenta found the hospice nurses to be even more confident, assertive, and imaginative than women in the general population.

Hospice nurses in Amenta's study (1984) rated themselves significantly more "deeply religious" than the nurses who worked in the hospital. This finding substantiates an earlier study conducted at the Royal Victoria Hospital in Canada (1976), in which hospice nurses who remained in the service, irrespective of religious affiliation, denomination, or intensity of church attendance, were more religious than nurses who left their positions.

Amenta (1996) compared spiritual care beliefs, attitudes, and clinical practices of oncology and hospice nurses. The oncology nurses were found to be significantly more religious while the hospice nurses were significantly more spiritual and more likely to incorporate spiritual care interventions into their nursing practices. Amenta does not

define "religious," but traditional definitions associate religion with an organized church affiliation and practicing of specific religious rituals designed to strengthen the faith of the individual church attender. Spirituality connotes an openness to other's beliefs and a connectedness that permeates one's being and daily activities. These findings concur with Amenta's (1984) earlier findings in which the traditional hospital based nurses were more concrete and task oriented than the free-thinking, imaginative hospice nurses.

Hospice nurses in Amenta's study (1984) were found to be better educated than their traditional counterparts and scored moderately high in purpose-in-life scores, with high scorers being characterized as "robust, optimistic, decisive, confident, [and] feeling in control of their lives" (p. 417). The hospice nurses were characterized as "extremely genuine, direct, gregarious, spontaneous, capable of warm involvement, and trusting" (Amenta, p. 418).

Perhaps in hospice, an innovative service on the cutting edge of the health care system, where nurses perform such a manifold function and take such heavy primary responsibility for complex autonomous activities and judgments, the tradition of subservience and dependence for nursing cannot prevail. (Amenta, p. 419)

Amenta (1984) summarized her findings with the cliché, "so a nurse is not a nurse is not a nurse" (p. 418), with her study shedding some light on the "frequently heard statement, everybody knows hospice workers are 'different,' but nobody knows quite how" (p. 417).

Rate of Burnout

Bram and Katz (1989) investigated burnout in nurses working with the terminally ill and compared hospice nurses to hospital based oncology nurses and found a significant difference between their burnout scores. Nurses working in hospital based oncology units were more likely to suffer from signs and symptoms of burnout when compared to hospice nurses. Hospice nurses tended to be reinforced by their work and by direct patient contact, rather than stressed by it.

For hospital based oncology nurses, Bram and Katz (1989) found a positive correlation between burnout and patient/staff ratio, hours of direct patient contact, and perceptions of support in the work place. For hospice nurses, Bram and Katz found a positive correlation between burnout and role discrepancy (conflict between their ideal and real work situation), and perceptions of support in the work place. For the hospice sample, there was a negative correlation between burnout and direct patient contact, meaning the more time that the hospice nurse had to spend

with his or her patients, the less likely he or she would be to exhibit signs or symptoms of burnout.

Descriptive data from the Bram and Katz (1989) study indicated that "hospice nurses perceived greater opportunity to express work-related feelings and to discuss problems in the work place than did hospital nurses" (p. 558). Hospital based nurses who experienced the highest degree of burnout were more likely to express work-related feelings and problems to family and friends, rather than at work.

"Hospice appears to be a less stressful environment in which to care for terminally ill patients than the hospital-based oncology unit setting" (p. 557). Bram and Katz concluded that for hospice nurses, "contact with their patients is not inherently stressful and is, indeed, what they value highly in their work" (p. 559).

Life Cycle

McDonnell and Ferrell (1992) sought to define the phenomenon known as the "life cycle of the oncology nurse" through formation and membership in the Oncology Nursing Society's "Life Cycle Task Force." The task force "came to a consensus of 10 'essential' or 'critical' concepts that represent the major influences throughout the life cycle of the oncology nurse" (McDonnell & Ferrell, p. 1546). These 10 essential concepts included critical incidents, essence of oncology nursing, patient and family outcomes, nature of

the work, balancing roles, influential people, volunteerism, role diversity, environment/culture, and specialization. The task force's findings provided a better understanding of the members of the Oncology Nursing Society, their experiences, and "how these experiences relate to an individual's career and commitment to the specialty" (p. 1550).

The following definitions from the McDonnell and Ferrell study were of particular interest to this researcher, because they were relevant to this study. The term "critical incident" was used by the Oncology Task Force to indicate a career or life changing event and was defined as an event "that occurred when a difference in patient outcomes existed, something went well or not as planned, something was typical, something was particularly demanding, or something captured the quintessence of what nursing is all about" (McDonnell & Ferrell, p. 1546).

The "essence of oncology nursing" referred to the nature of this specialty nursing care and was defined as "what makes something what it is and, without which, it could not be what it is" (McDonnell & Ferrell, p. 1547). The Oncology task force believed that knowing the essence of oncology nursing would contribute to their understanding of this practice area as a unique specialty.

The term specialization was defined by McDonnell and

Ferrell as the application, modification, or adoption of information or skills for a particular use, or "to become individual in some way by concentrating on a particular line of action or course of study" (p. 1550).

View of Work

Cohen and Sarter (1992) used phenomenological interviews together with participant observations on an in-patient oncology ward to obtain a "better understanding of how nurses caring for patients with cancer view their work" (p. 1481). Themes included the typical day, critical incidents, difficulties, and rewards. "Critical incidents" were utilized to capture the essence of oncology nursing and focused on acute physiologic emergencies, meeting patient's and family's psychosocial needs, empathizing with patients, and how these incidents related to the nurses' own lives. These critical incidents often elicited feelings of anxiety and unresolved personal issues. Difficulties for these nurses included "conflicts with peers and physicians, unexpected crises, and patients' suffering and death" (Cohen & Sarter, p. 1485). Rewards for the nurses in the Cohen and Sarter study came from comforting a distressed patient or their family, from success stories (when patients became free of disease and went home), or from receiving recognition from peers.

"Being There"

Nurses in the Cohen and Sarter study (1992), described the act of "being there" for their patients during "their most private moments of suffering and responding to the height and depths of their responses to this suffering" (p. 1485), as an integral part of the nature of their work with cancer patients. These nurses "described working with patients with cancer as being on the front lines of a war against death, disfigurement, and intense human suffering" (p. 1485).

Intrinsic and Extrinsic Motivation

Amabile, Hill, Hennessey, and Tighe (1994) developed the "Work Preference Inventory" to assess individual differences in intrinsic and extrinsic motivational orientations toward work. Elements of intrinsic motivation included self-determination, competence, task involvement, curiosity, enjoyment, and interest. The intrinsically motivated individual is driven with a passion for his/her work, gaining a deep level of fulfillment from what he/she does, and will "engage in work primarily for its own sake, because the work itself is interesting, engaging, or in some way satisfying" (Amabile et al., p. 950). Extrinsic motivational components included concerns with competition, evaluation, recognition, money, or other tangible incentives and constraints by others. The extrinsically motivated

worker will perform "in response to something apart from the work itself, such as reward or recognition or the dictates of other people" (p. 950). The extrinsically motivated individual is more impatient, demonstrating rigid behavior in task engagement, and lower levels of creativity in a variety of tasks when compared to the intrinsically motivated worker who "may strive to select work assignments that allow them to develop new skills, exercise creativity and become deeply involved in their work" (p. 951). Based on Amenta's (1984) work on traits of hospice nurses in conjunction with the findings from Amabile et al. (1994), one can conclude that hospice nurses are intrinsically motivated and this may account for the passion that these nurses exhibit toward their work.

Job Satisfaction

Grant, Nolan, Maguire, and Melhuish (1994) examined factors influencing job satisfaction among nurses. Grant et al. found that nurses were most satisfied with the intrinsic aspects of their jobs, with motivational factors including (a) job interest, (b) achievement, (c) responsibility and autonomy, and (d) recognition. "Nurses working in the community tended, on the whole, to be more satisfied and less dissatisfied than their hospital colleagues" (Grant et al., p. 619). One might suspect that because the majority of hospices are community based and the majority of hospice

care is performed in the home, hospice nurses would report a higher level of job satisfaction when compared to hospital based oncology nurses.

Lived Experience of the Oncology Nurse

Haberman, Germino, Maliski, Stafford-Fox, and Rice (1994) conducted a phenomenologic study of oncology nurses and the meaning of their work. They sought to identify factors that influenced nurses' decisions to enter nursing and to specialize in oncology. Haberman et al. (1994) found many formative personal experiences that influenced an individual's deliberate decision to enter oncology nursing, including childhood illnesses, family experiences with cancer, and role models within the profession. Critical events or "special patients" were also identified as factors influencing those who made a deliberate career choice of oncology nursing.

Haberman et al. (1994) found that "the reasons why nurses specialize in oncology are remarkably similar to the professional and personal rewards derived from daily practice" (p. 43). These reasons include the ability to practice holistic nursing with a strong psychosocial component, contact with special patients and their families, the ability to form intimate long term relationships, and the complexity of oncology care which challenges their nursing skills. Personal rewards included "the awareness

that many patients give far more to nurses than the nurses think they give to patients" (p. 45). Nurses also acknowledge they have learned from their patients and families many lessons relevant to their own lives which include learning about fear, love, trust, and keeping the important things of life in perspective.

Nurses in the Haberman et al. study indicated that chronic sadness of oncology patients and witnessing the physical wasting of cancer, coupled with the side effects of treatment were very difficult for them. The study participants also indicated that caring for a dying patient could be both one of the most difficult as well as one of the most rewarding aspects of oncology nursing.

Haberman et al. found the caring behavior of "being there," as in Cohen and Sarter (1992), to be a core concept for the oncology nurse. "Being with implies that the nurse is keenly present in the moment for patients and families and that no expectations are placed on patients to function beyond their immediate capabilities" (Haberman et al., 1994, p. 46). The oncology nurses in this study exhibited pride and a deep sense of fulfillment in their specialty area and the fact that "their mere presence often provided immeasurable comfort to patients" (p. 47). However, these same oncology nurses reported being frequently chided for their career choice and expressed that they seldom received

public esteem or the recognition they felt they deserved. Admonishments included, "How do you work with cancer patients all the time?" "It's so depressing." "Doesn't everyone die?" "How can you stand the suffering?" "Oh, you're the death nurse." Haberman et al. concluded that "these negative societal attitudes and stereotypes may actually help oncology nurses to crystallize their personal pride and identity as specialists" (p. 47).

Summary of Literature Review

Of the studies analyzed for this literature review, few of them differentiated between oncology and hospice nursing in the care of patients with cancer. For this thesis, the researcher separated hospice nurses from oncology nurses based on differences in orientation to care and treatment goals. Hospice nurses have made a definite shift or transition in their nursing care from the "quantity of life" orientation of oncology nurses who seek to prolong their patients' lives, to a "quality of life" orientation. As a result of this shift, hospice nurses try to make the best of an inevitable diagnosis by controlling symptoms for the dying patient so they can be free from pain to enjoy their remaining days with family and friends.

Amenta (1984) found personality and practice traits of hospice nurses to be dramatically different from nurses who work in the traditional hospital setting. Amabile et al.

(1994) developed the Work Preference Inventory to assess intrinsic and extrinsic motivation towards work. When comparing the findings in the Amabile et al. study (1994) to the traits of hospice nurses identified in the Amenta study (1984), it becomes clear that hospice nurses may value autonomy and be more intrinsically motivated when compared to hospital based oncology nurses. Bram and Katz (1989) found a difference in the burnout rate between hospice nurses and hospital based oncology nurses, finding that hospice nurses experience burnout at a significantly lower rate. Grant et al. (1994) found community based nurses (where hospice care is primarily practiced) to be more satisfied with their jobs than their hospital based colleagues (where oncology nursing is primarily practiced).

In the description of the "Life Cycle of the Oncology Nurse" and their career trajectory by McDonnell and Ferrell (1992), hospice nursing is only mentioned by inference as a "non-oncology nurse or those who provide care to patients with cancer but do not perceive themselves to be an oncology nurse" (p. 1550). Both of the phenomenological studies, Cohen and Sarter (1992) and Haberman et al. (1994) utilized that methodology to look at the lived experience of the oncology nurse to determine what made oncology nursing special, the essence of the oncology practice, and what motivated these nurses to enter nursing and specialize in

oncology nursing. To date there have been no phenomenological studies that examined the lived experience of the hospice nurse to determine what makes hospice nursing special, the essence of hospice nursing, or what motivates the nurse to specialize in hospice nursing. This study addressed this research gap and added to the body of nursing knowledge about hospice nurses and their unique specialty practice.

Conceptual Framework

The conceptual framework which guided this research study was a phenomenological perspective. Phenomenology is an investigation of the "lived experience," and seeks to describe and find meaning in ordinary, day to day activities of a group of people who are living the phenomenon under study. "Phenomenology is a way of thinking about what life experiences are like for people" (Lobiondo-Wood & Haber, 1994, p. 262). Bishop and Scudder (1991) believe the phenomenologic philosophy and approach to be well suited to nursing inquiry because it attempts to disclose the essential meaning of the human experience, which is the essence of nursing practice. Davis (1978) also states that "phenomenology provides a more perfect fit conceptually with the functions of clinical nursing and with many of the research questions that evolve from clinical practice" (p. 187).

"Phenomenology began as a philosophical reaction to the move by scientists to objectify human behavior" (Field & Morse, 1985, p. 28). Phenomenology had its roots in philosophy, and was developed by Husserl in the 1970's, in an effort to "establish a rigorous science that found truth in the lived experience" (Lobiondo-Wood & Haber, 1994, p. 262). Husserl (1970) considered phenomenology to be a philosophy, an approach, and a research methodology.

The goal of phenomenology is to find shared meanings or themes through in-depth interviews or conversations, in an effort to identify and describe the essential meaning or the essence of the lived experience. Phenomenologic language is descriptive in nature and "its purpose is to make the ordinary experience evident through reflection to clear intuition" (Ray, 1994, p.119). Phenomenology seeks to accurately describe the phenomenon under study from the perspective of those individuals who are experiencing it, and does not seek to generate theory or develop conceptual models. Generalizations within phenomenology are based on similar meanings or themes found within interviews describing the lived experience, not an exact duplication of the experience or its essence (Field & Morse, 1985).

"A primary requisite of phenomenology is that there are no preconceived notions, expectations, or frameworks present to guide researchers as they direct and begin to analyze the

data" (Field & Morse, 1985, p. 28). A phenomenological researcher accepts the experience as it exists in the mind of the individual, and "brackets" his/her own perspective as a way of setting aside personal biases or anticipations of the phenomenon throughout the interview process and analysis steps of the research process. The phenomenologist holds in abeyance his/her own experiences or knowledge "to allow data (the things themselves) to show themselves 'as meant'" (Ray, 1994, p. 129).

The interview process used to discover phenomenologic meaning by describing lived experiences, usually takes place through loosely semi-structured interviews. Ray (1990) recommends "presuppositionless" interviews, where the research questions are not predetermined, but flow from a clue and cue-taking process, after the initial query question is asked. "The phenomena of experience are probed with the participant until 'the thing itself' is illuminated and described" (Ray, 1994, p. 129). For the purpose of this research, a semi-structured interview guide was developed, including open-ended questions, and possible follow-up questions. The researcher had this guide available during the interview, and referred to the guide as needed, depending on the flow of information from the nurse participant.

Data analysis in phenomenology is a reflective process

involving sensitivity, intuition, and insight by the researcher. Thorough listening to tapes and re-reading of transcripts are necessary in order to thoroughly synthesize all of the participants' descriptions of their experiences. Each interview is analyzed individually for shifts in ideas and significant phrases, and then the interviews are collectively analyzed for central meanings to search for common themes. Bergum (1991) states, "The theme of an experience is the principle, or essence, that makes the experience what it is" (p. 64).

Phenomenological research includes the act of "confirming" with the study participants after the initial interview has been completed or analyzed. Confirming ensures that the data are complete and that all parameters of the experience have been described in the researcher's findings. One of the benefits of confirming, is that it reduces interviewer bias and affirms the accuracy of the researcher's interpretation.

Phenomenological findings are best reported using the study participants' own words to capture the essence of their experiences. Exemplars, or personal knowledge "revealed through stories is contextualized, personal, never replicable, and full of life experiences that are not explained" (Bergum, 1991, p. 62). Stories allow the reader to be drawn into the lived experience and moved by the

participant's own words instead of the interpretations of the researcher. Quotations or exemplars help to illuminate themes, and a purposely selected participant's story "reveals the landscape of her life, that is, her situation and the context from which her words come" (Bergum, 1991, p. 63).

Summary

Research reviewed for this study indicates that hospice nurses are distinctively different from other nurses, not only in their orientation to care and treatment goals, but in their work motivation, job satisfaction, burnout rate, and personality traits. Some research has been conducted that chronicles the lived experience of the oncology nurse, but to date, no research has explored the lived experience of the hospice nurse. Phenomenology was the ideal research methodology to explore the unique values or life perspectives of hospice nurses in order to describe in their own words the essence of hospice nursing and what makes this unique type of care special.

Chapter 3

METHODOLOGY

Research Design

A phenomenological design was used in this research to explore the lived experience of the hospice nurse. "The task of phenomenology is to return to the familiar and reexamine what we believe we already know and understand by reflectively bringing into awareness what has been taken for granted" (Powers & Knapp, 1990, p. 106). A phenomenological approach was chosen because previous research had never been conducted on hospice nurses to capture in their own words, as only they could describe, why they chose this field of specialization, what they see as the essence of their practice, and why it is so special to them.

Researcher's Perspective

This researcher used "bracketing" to recognize and hold in check personal biases on the research topic during the preparation and interview phase of this study. Bracketing is a common practice among phenomenological researchers. "By becoming aware of personal biases, the researcher is more likely to be able to pursue issues of importance introduced by the participant, rather than leading the participant to issues deemed important by the researcher" (LoBiondo-Wood & Haber, 1994, p. 263). During the data gathering phase of this study, the researcher demonstrated

bracketing by taking cues for questioning from the respondents so as not to lead them. This researcher asked participants for clarification throughout the interview process and solicited detailed explanations of experiences, so that no element of an incident or emotion were left unstated that would require the researcher to "fill in," "understand," or "interpret" concepts from her own personal knowledge, perspective, or experience.

Subjects

In order to be eligible for this research participants needed to be English speaking, age 21 years or older, and registered nurses currently working as hospice nurses in the community. Participants for this study were recruited from the local community of hospice nurses from hospices within the Bay Area that were listed in the National Hospice Organization's "Guide to the Nation's Hospices" (1995). Flyers (see Appendix A) were distributed and posted at local community based hospice agencies which sought registered nurse volunteers for this research. Participants self selected for inclusion in this study by responding to the flyer and contacting the researcher by phone. The researcher pre-screened the candidates over the phone for eligibility, using the "Phone Data Collection Tool" to collect demographic, employment, and educational information (see Appendix B). At this time, candidates were also asked

one simple, open ended question, "What made you decide to call me?" to ascertain the candidate's ability to speak clearly, make themselves understood, and to express themselves freely.

Sampling

This process yielded five study participants who were purposively selected to provide the researcher with a rich informant pool of hospice nurses with varying degrees of education and hospice experience. The researcher deemed this sample size to be adequate because of the in depth nature of the interviews. Phenomenologic interviews result in a "large volume of verbal data that must be analyzed and....This type of design tends to emphasize intensive and prolonged contact with subjects" (LoBiondo-Wood & Haber, 1994, p. 302).

Setting

The interviews were held in a mutually agreed upon location, away from the homes or places of employment of either the informants or the researcher. The places selected for the face-to-face interviews had a minimum of interruptions and ensured privacy for ease of open communication. Locations included restaurants, cafes, and parks.

Informed Consent

The informant's written informed consent (see

Appendix C) was given voluntarily, without coercion, in order to be included in this study. Participants were informed that they might feel discomfort or embarrassment when they were being interviewed or tape recorded. Participants were also informed that they might feel a range of emotions when remembering and sharing specific patient care experiences or encounters. Participants were told that if they felt uncomfortable with any of the questions they could chose not to answer. Subjects could refuse to participate in this research study or any part of this study, and could withdraw from participation at any time, without prejudice to their relations with their place of employment or San Jose State University. Risks to individuals who participated in this study were minimal, and no tangible benefits were provided as a result of this study, excluding refreshments served during the interview.

Confidentiality and Data Access

The identity of participants and the identity of the agency where they were employed were kept confidential. Numbers, rather than names, were used for storing, transcribing, and analyzing the audiotapes. Audiotapes and demographic information were kept in a locked box at the researcher's home, to which only the researcher had access. Audiotapes were erased after the interviews were transcribed. Information that could identify study

participants was destroyed after the study was completed.

Costs/Compensation

Neither the subject nor his/her institution, were compensated for participation in this study; however, depending on the location of the interview, the researcher paid for any food or beverages served during the interview process. There was no cost to the hospice nurses who participated in this study.

Research Procedures

Human Subjects Approval

Human Subjects approval was sought and obtained from the Institutional Review Board at San Jose State University prior to soliciting hospice nurse volunteers or collecting data for this research. Obtaining this approval ensured that this research was in compliance with the regulations for the protection of human subjects (see Appendix D).

Data Collection and Instrument

After obtaining informed consent, each study participant was interviewed individually by the researcher, utilizing a semi-structured interview guide (see Appendix E) composed of open ended questions to ensure that the nurse participants determined the direction that their answers took. Throughout the interview, the researcher asked impromptu questions to "clarify any unclear answers to be sure of the meaning of the nurses' experiences" (Cohen &

Sarter, 1992, p. 1482). The interviews lasted between 1.5 to 2.5 hours. A total of 9 hours of interviews occurred, with a mean interview length of 1.8 hours. The interviews were tape recorded so that no given information was omitted, for ease of re-call, and for analysis. The audiotaped interviews were transcribed verbatim. Once the tapes were analyzed, a copy of the analysis was sent to each research participant for review. The researcher then contacted the informants by phone, or requested a short meeting in person to determine if the researcher's composite analysis of the interviews fit with what the subject stated, and captured the true meaning of hospice nursing and the lived experience for that subject. All of the informants confirmed that the researcher's analysis and presentation of themes were an accurate depiction of their lived experience. None of the informants had anything to add to the findings. This post interview contact and review of the findings by the informants confirmed that bracketing had been effectively utilized by the researcher and that the researcher's analysis was a accurate representation of the thoughts and feelings of the hospice nurses and not that of the researcher.

Data Analysis Procedure

Transcripts were analyzed by the researcher using phenomenological techniques involving reflection,

sensitivity, intuition, and insight. Each transcript was read and then re-read multiple times as the researcher searched for central meanings or themes that would accurately depict the lived experience of the hospice nurse. Notes were made in the margins of the transcripts during each reading in order to note recurrent themes and their locations within the transcripts. This researcher would ponder and reflect on the words of the hospice nurses between readings as possible themes began to emerge and become clear. A code book was developed by the researcher to record key words and possible themes with page numbers for each separate interview. A cross referencing system was then set up which combined similar thoughts or ideas for all five interviews onto theme logs. Each theme log was then reviewed for representative quotes that would best illustrate a particular theme and the draft analysis of the interviews was then complete. Examples of verbatim text were selected as exemplars to illustrate the themes and are included in the results section of this study.

Participants were then asked to read a written draft of the findings to validate the analysis and confirm that the researcher's interpretation captured the dimensions of their lived experience. Each of the informants confirmed that the researcher's analysis was accurate, and that nothing needed to be added to the findings. Themes were then finalized and

separated into primary and secondary themes. Both levels of themes were distinct and unique, but the secondary themes could be grouped under primary themes and served to organize ideas and thoughts along similar lines.

This final analysis is a synthesis of themes derived from the interviews and describes the phenomenon of the lived experience of the hospice nurse.

Chapter 4

FINDINGS AND INTERPRETATIONS

Demographics

All five participants in this research study were female and worked as hospice staff nurses in community based hospices within Santa Clara County. Participants' ages ranged from 33 to 60 years old with a mean age of 44.6 years. The study participants worked from eight to 25 years in nursing with a mean of 15.2 years. These nurses had a combined total of 76 years of experience in the nursing profession. Study participants worked from 3.5 years to 8 years as hospice staff nurses with a mean of 6.1 years of experience in hospice, and a total of 30.5 combined years in hospice nursing. Study participants spent from 18% to 75% of their nursing careers working as a hospice nurse with a mean of 40% of their nursing careers spent giving care to the terminally ill in a community based hospice program.

Level of education for study participants varied. All participants were registered nurses, but educational degrees ranged from Associate to Baccalaureate to Master's prepared nurses. One participant was licensed as a Nurse Practitioner, but was not practicing within this scope. Another nurse received her Bachelor's Degree in Sociology and worked as a social worker before returning to school for an Associate Degree in nursing.

All of the study participants were members of the California Nurses' Association, which administers their collective bargaining agreement, with membership being a condition of employment. Two of the nurses stated they were members of the National Hospice Organization "because our agency is a member," but they did not personally belong or pay individual dues. One of the study participants was a member of the American Holistic Nurses' Association.

Two of the study participants were certified in their current area of practice as hospice nurses, one was a Certified Trauma Nurse and one was a Certified Massage Therapist. Two of the five study participants were not certified in any nursing specialty (see Table 1).

Interview Impressions

Study participants were articulate and eager to talk about their professional experience and "why we do what we do." Informants showed a willingness to freely share patient care experiences with someone who was willing to listen "and let me ramble on and on about what is important to me." These nurses displayed a wide range of emotions, laughing at times or crying openly with tears streaming down their faces as they were touched by memories of special patients and families. These nurses were never at a loss for words or examples to describe their work with the terminally ill. At the end of each interview every nurse

Table 1

Hospice Nurse Demographics

RN	Age	Years in Nursing	Years in in Hospice	Education	Specialty Certification
1	60	25	7	MSN, NP ^a	Hospice
2	44	8	6	BSN	--
3	37	19	3.5	ADN	Trauma
4	49	13	8	BA ^b , ADN	--
5	33	11	6	BSN	Hospice CMT ^c AHNA ^d

Note. Mean age for all participants was 44.6 years. Mean of 15.2 years in nursing. Mean of 6.1 years in hospice nursing. Mean of 40% of nursing career spent in hospice nursing.

^aLicensed Nurse Practitioner. ^bBachelor of Arts Degree in Sociology. ^cCertified Massage Therapist. ^dAmerican Holistic Nurses' Association.

expressed his/her thankfulness at having the opportunity to reflect on "the work" and put into words feelings and experiences rarely shared outside of the "hospice inner circle" made up of immediate family or members of his/her own hospice team.

Themes

After each taped interview was transcribed this researcher read and re-read each interview multiple times utilizing phenomenological analysis methods to identify common themes throughout the interviews describing the lived experience of the hospice nurse. Thirteen primary themes evolved from the interviews, including: The Death Taboo, Team Spirit, Holistic Care, The Inhospitable Hospital, Dual Autonomy, Making a Difference, Death is Not the Enemy, A Greater Awareness, Divine Intervention, Equipped for Hospice, Discovering Death, The Hospice Vocation, and The Learned Experience. Fifteen secondary themes also emerged. These secondary themes were: Importance of Psychosocial, Importance of Spirituality, Patient Autonomy, Nursing Autonomy, Enabling and Empowering, Being with the Dying, Being in the Moment, Beings from Beyond, Life After Death, Simplicity, Quality of Life, Fragility of Life, Importance of Relationships, Order in Life, and Death is the Great Equalizer. These secondary themes were distinct, but could be grouped under main themes and served to organize

ideas and thoughts along similar lines. These secondary themes provided further insight into the primary themes by describing unique aspects and dimensions of these dominant themes in more detail (see Table 2).

The following section of this paper will discuss the themes and their interpretations in more detail. Primary and secondary themes have been grouped under three major categories: (a) unique nursing perspectives, (b) life preparation, and (c) life perspectives and values.

Unique Nursing Perspectives

The Death Taboo

The hospice nurses in this study freely shared experiences with this researcher because the interviewee was approached with a listening ear and a non-judgmental attitude. This is not the usual experience of the hospice nurse. One nurse stated that "If you want to stop conversation at a cocktail party faster than anything on earth, say, 'I am a Hospice Nurse' and there is dead silence." Another nurse stated that "not many people know about [hospice]; not many people want to talk about it; the society is very definite in denying it; there is a big secrecy about it."

The hospice nurses described others' impressions of their work as morbid, morose, and depressing. "When I try and discuss it with my husband's family, they think I'm

Table 2

Themes

Unique Nursing Perspectives		
1.	The Death Taboo	
2.	Team Spirit	
3.	Holistic Care	a. Importance of Psychosocial b. Importance of Spirituality
4.	The Inhospitable Hospital	
5.	Dual Autonomy	a. Patient Autonomy b. Nursing Autonomy
6.	Making A Difference	a. Enabling & Empowering b. Being With the Dying c. Being in the Moment
7.	Death is Not The Enemy	
8.	A Greater Awareness	a. Beings From Beyond b. Life After Death
9.	Divine Intervention	
Life Preparation		
10.	Equipped for Hospice	
11.	Discovering Death	
12.	The Hospice Vocation	
Life Perspectives and Values		
13.	The Learned Experience	a. Simplicity b. Quality of Life c. Fragility of Life d. Importance of Relationships e. Order in Life f. Death is the Great Equalizer

morbid, I mean I might as well say I'm a funeral director."

One nurse stated:

My friends and family always ask me: When are you going to change jobs? Why don't you get another job? Why do you do this? It's kind of like nobody ever asks you what you do, and if you tell them, they kind of go "Oh" and then change the subject, because it's very uncomfortable for them, and so in that way it's very lonely sometimes.

One nurse told of a story she recently overheard at a conference and has decided that this is going to be her new explanation to shed a different perspective on the work that she takes pride in. She related:

I just don't care if I do hospice work anymore, because my sister-in-law is an OB/GYN nurse and she says, "Oh, I birth babies" and everyone goes "Oh, how wonderful that must be!" and then I say "I'm a hospice nurse" and they go, "Oh?" It's like immediate silence in the room. So now I tell people that "I birth people to the other side."

The nurses interviewed for this study feel there is a great deal of respect for the hospice profession and that other health care professionals state, "I could never do it. I don't understand how you do [hospice], but I admire you, and I'm glad that somebody can do that." One hospice nurse

explained it this way:

Other nurses can't quite fathom [hospice] on an emotional level. They still feel like it must be awful and depressing and discouraging because our whole medical profession, doctors and nurses both, are fundamentally and in a very general way trained and expect to make people better, so it's very hard to accept when people are going to fail.

Team Spirit

These hospice nurses value members of the hospice team, usually comprised of other nurses, home health aides, doctors, social workers, chaplains, grief/bereavement counselors, physical therapists, occupational therapists, speech therapists, or volunteers. The team environment offers the hospice nurse a supportive environment of other professionals who understand the work and the associated stress; because they are also involved with the work.

The nurses described the interdisciplinary approach as incredible teamwork with the ability to work very closely with other disciplines. The nurses spoke of "pulling in other team members...when deficits are identified in the [on-going] assessments." These hospice nurses believe that the interdisciplinary team approach adds to the patient's quality of life and that "what we can do as a hospice team, and me as a hospice nurse, is to make each day as

comfortable and as quality-like as we possibly can for as many days as there are left."

The nurses described very difficult patient care situations, where different disciplines offered different perspectives and resolutions to death and dying problems, and in which all work together to accomplish similar goals. They debrief and support each other in some very difficult cases, and through one-on-one experiences with other team members they problem solve and cope with possible job related stressors or burn-out. One nurse described it this way:

I think that's why our team is so close because we're the only ones that really understand what we do. Our patients and families understand what [we] do because they are there and they always say, "Gosh, I never even understood what hospice was about before."

For the nurses in this study, hospice was their first real exposure to an interdisciplinary team approach to patient care and this element makes this type of work extremely satisfying. Hospice care is indicative of a real team approach. One nurse describes it this way:

I think that it's something that's really valuable in doing hospice work....This is probably the first job I've ever had, even when I worked in the hospital I didn't work so closely with social workers, didn't work

so closely with physicians; it just didn't feel like a team approach. I don't remember us having meetings to talk about a patient and how they're doing. I don't remember involving a chaplain, or those kinds of things. It's just a whole team effort [with] coordination of care that I really like.

Holistic Care

These hospice nurses value the holistic perspective and broad scope of hospice care. These nurses care for their patients not only physically, but also psychosocially and spiritually. The hospice team concept also supports the holistic model of care as different licensed professionals offer their expertise on specific patient or family problems. One nurse described the holistic care in hospice in the following way.

I'm not a technology person. I much more enjoy simplicity and being able to focus on more of the psychosocial, and the spiritual, and not being so focused in on the medical when I don't have to. I mean I do it when it's necessary...but I like having time to focus on the mind, body, and spirit.

These hospice nurses believe that it is this holistic aspect of hospice care that best prepares patients and families for an inevitable death and leads to comfort care and quality of life with resolution of unfinished business

as the best outcomes for the dying patients and their families. One nurse described hospice nursing "as more dynamic and global" than other types of nursing, "with the administrative support to talk and listen to patients."

These hospice nurses feel that it is their responsibility to care for the whole person, first tackling symptom management, then helping the patient to get his/her business in order so that a peaceful death can occur physically, mentally, and spiritually. These nurses strive to reframe traditional care of the dying from thinking of the patient as "Gloria with cancer to Gloria as a human being." One nurse described the action of reframing within the context of holistic care in the following way:

I attempt to move care of the dying patient towards finding a whole new aspect of who that person is. Instead of focusing on this body anymore, we must address the fact that these people have spirits, that they have souls, that they have emotions, that they have minds. All of these things are as important, if not more important at this point in their life than at any other time, and need to be addressed....They have care needs that need to be expressed, tended to, and cared for.

These informants practice, value, and receive support for alternative nursing interventions within the context of

hospice's holistic practice model. They describe the importance of touch and people being touched, even when their patients are seriously ill. Hospice nurses may use therapeutic touch or massage to reduce communication barriers and to assist in building their relationship based on trust. Touch and massage also have the added benefit of providing distraction and serving as alternative pain control techniques to augment narcotic pain control.

Importance of the psychosocial. Hospice nursing encompasses more than just clinical or technical expertise. Nurses who value performing hands on tasks for patients or are not comfortable exploring difficult feelings, may not last long in hospice nursing. One of the nurses described this finding this way:

I believe that hospice nurses are a certain kind of people with certain kinds of skills. I have seen some nurses go into hospice and not be comfortable with this kind of work and not stay long because it didn't suit their value system.

Hospice nurses value the psychosocial realm of nursing and have found support for this scope within the hospice setting. "Hospice nursing is extremely rewarding to me because I feel like it is expected, and allowed, and desirable to actually take the time to explore the emotional needs of patients, and it is not nearly as task oriented."

Hospice nurses often work as facilitators to help families to communicate and reflect on their lives and their life's work. One nurse described her role as a facilitator within the psychosocial realm in the following way:

To help patients communicate with their families and their loved ones messages and feelings of love and support and continuity of their lives, meaningfulness of their lives. That they would have time to work through and do these things so that there was a sense of completion in the life cycle along with the sense of physical comfort, a sense that both the patient and the caregivers were prepared for this end of life experience. Then I would feel like that was a very positive experience with a good outcome.

These hospice nurses feel that the ability to help patients and families explore emotional and psychosocial issues is so integral to their practice that they would leave hospice nursing if outside constraints prohibited it, or if administrative support for these vital interventions were withdrawn.

Importance of spirituality. These nurses view the spiritual domain of hospice care as supportive and valuable for dying patients and their families. Support for the spiritual realm is seen as essential by hospice nurses, since patients who come closer to dying, and families who

have lost loved ones, often report experiences, feelings, or "sightings" that have no explanation outside of a spiritual context. Spirituality can help to explain or give meaning to a premature or unexpected death and can be utilized as a coping strategy for patients and families. One nurse related this conversation with a patient who felt more at peace with dying after such an experience:

"I feel safe now, cuz I died about seven times on the table, my heart stopped and they brought me back every time. I was never really scared after that." I told her, "I've had a lot of patients with real experiences like that....They experience some presence of something that is very comforting and it's like they're not afraid after that." The patient looked at her husband and smiled stating "See honey." I asked her to explain more. "Well, the funniest thing is that they're always on my left, but there are three people and they were always right there by the table watching over me, guarding me, being right there with me. I can't see their faces, but I just know they're there and they're safe."

These experiences can offer hope, help the patient to feel safe, and validate for the patient and family their belief in an afterlife. The hospice nurse is able to assist the patient to find meaning in these experiences within the

context of his/her belief system.

Hospice nurses are open minded to religious beliefs and practices that may be different than their own.

I have been doing a lot of experimenting with different religious traditions....I really try to support my patients wherever they are coming from, wherever their spiritual beliefs come from, whether that be religious or just manifested in other ways. I think that for me spirituality is talking about where [we] are going, where[we] have been, and what's it all about. I'm very comfortable talking with my patients about what their death might look like and where I think they might go, and I share a lot of books and a lot of near death experiences. They seem to find a lot of comfort in that kind of thinking, that there is possibly something after this. But some people are real clear that they don't want to talk about that at all. I just respect that, and kind of go where they are and support them in their beliefs.

The Inhospitable Hospital

These nurses entered the specialty of hospice nursing out of a dissatisfaction with traditional treatment of dying patients and care of families in the hospital environment. Prior to entering hospice, these nurses had a difficult time "pushing treatments" on patients, force feeding, and

hydrating them. Futility of treatment was a difficult aspect of hospital care of the dying, often prolonging the inevitable and making death for both the patient and family much more difficult. Nurses who provided hospital based care of the dying experienced ethical conflicts on a daily basis. They pumped people full of medicine that they knew would not cure them, without talking to them about what was actually happening to them, and without acknowledging that they would soon be dead. One nurse described a typical situation:

I was working in the ICU and I got tired of reviving people who I shouldn't have been reviving, and who didn't revive anyway. [I was] watching people die in slow motion, with a lot of pain and suffering and not being medicated for what they were experiencing. [I was] seeing people overloaded with fluids for no reason, just because somebody needed to do something to justify them being there, and they died anyway. And they died uncomfortably, and families weren't prepared or included in the care. It bothered me and I wanted to get out of that.

With the introduction of managed care and the increase in for-profit health care institutions, hospital nurses were forced to do more with less, leaving no time for what they valued as nurses, patient interactions and "the psychosocial

stuff which is what initially attracted me to nursing." Hospice nurses described the hospital environment as extremely frustrating and limiting.

Med-Surg nursing was very focused on treatment, not so focused on someone's spiritual well-being, or their emotional well-being, or the psychosocial aspects of their health care. I found being in a hospital very limiting. I didn't feel like I could survive that kind of care. In the hospital it was really difficult for me.

The hospital based nurse-client interactions were time limited and didn't allow for establishing rapport and trust, which are essential for a therapeutic relationship. This rapport is developed and nurtured in hospice. Trust is the essential foundation necessary for open communication, vital to fostering the asking of questions, and integral to truthful information exchanges about the harsh reality of dying.

In hospital nursing, very rarely does the hospital nurse get to know what happens after the patient goes home. Hospice allows for continuity throughout the terminal phase and allows the nurse to go into the home and see the environment and the family that will influence the care and death of his/her patient. Hospital nursing "is a defined, small interaction with a small area of the patient's life or

experience and then it is over, and in hospice nursing it can be pretty intense until the end and then even after that." Bereavement, as a unique concept to hospice, allows the nurse and hospice team members to continue to visit with families up to a year after the patient's death. This extended contact allows for closure for the nurse and support for the family, an aspect of care of the dying that was missing from hospital based care.

Dual Autonomy

These hospice nurses value "autonomy for all human beings," both for the patient and for themselves in their nursing practice. Hospice nurses feel that "all beings should have the right and opportunity to experience that which they desire, without being influenced by constraints of outside sources that are contrary to their belief system or ethics."

Patient autonomy. Hospice nurses have watched the terminally ill patient die both in the hospital and at home with hospice. They value autonomy in both settings as each patient's right to self determination. Dying patients have "been entrenched in the medical system. They've had a disease and had to be treated by a cold impersonal system of medicine that tells them what they need to know, what they need to do, and how they need to do it." These nurses recognize that their patients have an easier death than

other terminally ill people not associated with hospice. Hospice nurses feel that removing the dying patient from the hospital and caring for them in the home gives the patients more control over their life and death, instead of the hospital and the doctors controlling the dying process.

These hospice nurses attributed the easier death of hospice patients at home to the patient having the ability to make decisions about his/her care and to be supported during and after decisions are made.

In the hospital I would be pushing fluids on people and not really feeling that it was OK to talk with the families about other alternatives. It was just about following doctor's orders, and how much pain people would be in, and not being able to give them their medicine whenever they wanted it, whereas a person in hospice, imagine, she would know when she was in pain, but these other people two doors down didn't, the doctor did!

These hospice nurses feel that patients have the right to choose aggressive treatments if they want to lengthen their life, but as health care professionals we also have an obligation to offer the alternative choice of palliative treatment, where care is focused on quality of life. In hospice the patient has the autonomy to weigh alternative choices and to make decisions as to what they want their

death to look like; they decide if they desire treatment, the degree of treatment, or if they want no treatment at all. One nurse described patient autonomy in hospice as follows:

I feel like in the home, I can educate, I can inform, but ultimately they have control of what they want to do. I just really like the control and decision making being up to the patient as long as they're informed and they're educated about what their choices are and the consequences of their choices.

Hospice nurses believe that in order to support the patient in his/her choices that it is important for the hospice nurse to enter the relationship without an agenda and meet the patient where they are. Hospice nurses are keenly aware that they can't fix everything and don't have all the answers, but "that the expectation is that you will be there for them and help them to seek out the answers to their problems for themselves."

Hospice nurses have to be strong patient advocates. Often times the hospice nurse acts as a liaison or mediator between patient and family members to support patients in their right to determine how and where they wish die. One nurse relates this story:

I had a family where the husband was dying and the wife was sternly neurotic. They had three children, all

successful, and all had very different ideas about what should happen with dad. One thought dad should be in the hospital, one thought that dad should be on IV's, and one was supporting dad in his wish to stay home. There was a lot of arguing and estrangement. I needed to spend a lot of my time telling the wife and the husband that "It's OK. It's your choice, it's your death, you get to choose." There was one crises after another. One son was always threatening to take dad to the hospital. I worked with the children constantly, reinforcing that "You have got to do this. This is your dad's last wish and it won't be much longer." In the end they were able to pull it off during the last 12 hours of dad's life. They rallied around dad while looking at an old photo album. They were all crying and hugging each other while stroking dad and saying "We love you dad." Dad died at home surrounded by his family.

Nursing autonomy. Nurses in this study also value the autonomy that they are able to experience and exercise in their hospice nursing practice. The nurses expressed that "this is the most important job that I have ever done, both for my life and the patient's." The hospice nurses reported that there is support and acceptance for "imaginative and creative problem solving in hospice, and often that wasn't

appreciated in other types of nursing." These nurses feel that "it is not the work itself that would cause me to leave the hospice profession, but lack of support to do the work as I feel it should be done which would cause me to leave the work that I love."

These hospice nurses described a practice environment where they were given the autonomy to work with the patient to find the best combination of interventions to control symptoms. The informants described very collegial and respectful relationships with physicians and they feel free to consult with them if necessary.

Hospice nurses need to feel comfortable with their own autonomy, because on a daily basis, they make independent care decisions within the scope of hospice standing orders. "To be a hospice nurse, you have to have quite a bit of autonomy, because you are out there, just yourself with these patients and families, trying to judge where they are at." These nurses valued going into a home, assessing a situation, figuring out what the care needs were, and how these needs and interventions differed from family to family. Hospice nurses are excellent clinicians and consider themselves to be experts in pain control and symptom management. They reported being sought out by other professionals who were less comfortable taking care of the needs of dying patients and frequently offered their

services and expertise on a consultant basis. One informant described this finding as follows:

There has not really been a good deal of research for [hospice] practice in the area of symptom management. And so the hospice nurses tend to be more knowledgeable about that. There's a little bit more of a responsibility on our part to kind of move the care plan in the direction that it needs to go, educating doctors along the way, rather than the other way, you know, doctors educating us about what they feel needs to be done. It is different from [acute care] nursing as it is very autonomous.

Making a Difference

Hospice nurses feel that their care makes a difference in the life and death of the terminally ill patient and the experiences of their families. One nurse described a patient care situation in which she made a difference by helping the family to understand and accept the philosophy of hospice care.

I was making a hospice evaluation visit on a patient with extensive abdominal cancer whose life was being maintained by technologies and tubes that consumed the family. I was trying to convey to the daughters what being on hospice meant, and at this point I asked "What is your goal for mom?" They agreed that they

wanted to keep her comfortable and this gave them the opportunity to begin to think about something different, i.e., that means "I know you're spending a lot of energy worrying about her wound...and these bags, and...this catheter, and doing all of these things, because right now that is the focus." I asked "Wouldn't you rather be spending your energy and time just being with mom and praying with mom, and singing with mom and holding her hand?" In that moment the experience for them was reframed into, "What a relief. We don't have to focus on her cancer anymore. We can just put that cancer on the back burner because we're not going to be doing anything with that, but we can still treat mom and be with mom."

Hospice nursing allows these nurses to feel good about themselves and the work that they do. "Making a difference is what makes hospice nursing so rewarding to me". Hospice nurses provide a service that makes a difficult situation a little easier. One hospice nurse described making a difference in the following way:

I have a firm belief that this process, is going to happen anyway. This person has a terminal illness. Death is going to happen, there isn't going to be anything that's going to stay this off, and if it were not for my visits and interventions, it might not go as

smoothly as it does go. I know that my care as a hospice nurse makes a difference in the patient's death and in the life of the survivors.

Nurses reported seeing the families of their patients in the mall or at the grocery store months or years after a patient's death. Families remember the nurse, thank her, "and show such appreciation, always giving positive feedback about how well the death went and how supported they felt. They let me know that if it wasn't for hospice they could not have done it."

Enabling and empowering. Two of the most important factors discussed by these nurses when looking at the difference that their work makes are "enabling" and "empowering" those involved with, and affected by the dying process, to feel like they can do what ever needs to be done. Hospice nurses in this study empowered their patients to make decisions about their care. These nurses enabled caregivers to feel empowered to support the patient in their journey, physically, emotionally, and spiritually, through actions and interventions that the nurse had role modeled or taught. One nurse described the ways that she enables families to support and empower the patient:

I see my job as enabling the family, the caregivers, and the patient to get through this experience with my ongoing support, interventions, assessments and

teachings. Because it is really the caregivers that are providing the care. I am just coming in and kind of coaching and supporting them along their journey.

Hospice nurses instill confidence through their interactions and interventions and this feels empowering to both the patient and the caregivers. The hospice nurse instills in her patients and families a sense that they can do anything. Another informant suggested:

I can teach, show, present, and enable somebody to take care of some problem that they couldn't have if I hadn't been there, and that I can leave knowing that they will be able to take care of it when I'm gone. They now have the tools to do what needs to be done. It's like giving a "hand, not a hand-out." Really showing them that they can do it, that they are capable of doing it, and then enabling them and empowering them to do it [sic].

Hospice work empowers patients by giving them permission to stop clinging to an existence that is sustained by tubes and embrace the remainder of their life with whatever it has to offer. "My job is empowering them to have it look like what they want it to look like and give them the support to do that." Hospice helps families and patients to feel empowered by letting them know that it is OK to give up the fight, and reinforcing that they are

giving good care. Hospice nurses are "always giving patients and families 'permission' to stop the feedings, or that it is OK not to drink or it is OK to take as much medicine as you need to be comfortable." Another informant stated:

I think that it is pretty rare that you don't see people stretch to as far as they're able, to watch people be empowered to do things that they think they can't do: "I just know I can't take care of this patient, I know I can't do this," and then to help them along in this journey and watch them grow, and just kind of grow right along with them.

Hospice nurses listen to families and acknowledge that care of the dying is hard work. They assure them that once the death is over they will not regret the care. One nurse described this care in the following way:

That for caregivers this care is their last loving gift to this person that they have cared for. And when [the caregivers] look back on this situation, when their loved one is gone, they are going to appreciate so much that they kept this person at home.

This reframing of the caregiving situation enables the caregivers to feel satisfied and empowered about the care they gave, even after their loved one is gone.

Being with the dying. Hospice nurses feel that "being

there" is also one of the defining factors that makes a difference in the life and death process of terminally ill patients and their families. Being there for the hospice nurse encompasses more than just being present with a patient who has cancer and is facing the uncertainty of cure versus death. "Being with the dying" is being there for someone who is confronting his/her own mortality with unquestionable certainty. The hospice nurse assists the patients in "making decisions about how they want it to go; with the nurse often having to honestly answer difficult questions about what the end will look like, so the patient and family will be prepared for the inevitable."

Being with the dying also acknowledges that this process may look different for different people, and that in order for the nurse to be able to support the patient in his/her choices the nurse must support these differences. "I love the fact that we're multicultural over here, it's really incredible for me to learn all of the different ways [of] being with the dying and ways of being with loved ones that goes on."

For the hospice nurse being with the dying means being present during an intense and emotionally charged time in people's lives. Even though the hospice nurse may feel uncomfortable, he/she acknowledges these feelings and offers comfort to the dying patient and the family. These nurses

have learned how important saying "good-bye" is for the grieving process and they are there to "support families in crying and being angry without doing something that's going to make them feel like it's not OK for them to express their emotions." Hospice nurses validate these feelings, discuss these feelings, and work very hard not to do "something that may let them know either on a conscious level or a subconscious level that it is not OK or that I'm not comfortable with it."

Hospice nurses observed that most people are uncomfortable being with people who are dying because they don't know what to say or do. One informant described being with the dying in the following way:

Being with the dying is the ability to be with people who are experiencing a wide range of emotions, and for me, not feeling like you have to fix it, but being OK with just being there with the dying and their feelings, whatever they may be, and not feeling like I have to do something to make it go away because I'm uncomfortable with their expression of feelings.

Hospice nurses have the opportunity to be with the dying daily throughout the course of their work. However being with the dying is often new and scary for the caregivers, and it is up to the nurse to role model and teach them to do this difficult task. One nurse stated, "I

think because I am not afraid of [death and dying] that people sense that. People say to me a lot, 'You're so calm, you seem so peaceful, you make me feel less anxious because you're not anxious about it'." One of the most difficult responsibilities for the nurse is to help families to acknowledge and accept that there are problems that can't be fixed and that it is OK to experience feelings of sadness and anger. One nurse stated:

The biggest thing that keeps coming to me is the ability to be with people who are dying, who are suffering, who are experiencing the gamut of human emotions and not feeling the urge to fix it, but being comfortable and able to be with people who are going through this.

Being in the moment. For the hospice nurse, being there expands into "being in the moment." The act of "being in the moment" brings significance to a particular moment as it occurs, and acknowledges that the nurse's mere presence with the patient and the family makes a profound difference in the life or death of the individuals who are present, witness, or experience the moment as it occurs.

Being in the moment means accepting where the patient is on any given day and working from his/her agenda, because every hello may be a goodbye. "You have to be in the moment in hospice, that's all there is left for people that are

dying is 'this moment' and what it holds." With each nursing visit the hospice nurse must be prepared to meet the patient where they are and help them to deal with whatever issue is troubling them on that day, because the patient must "take each day one at a time so that whatever time someone has left can provide as much quality as possible for them."

Being in the moment requires flexibility on the part of the hospice nurse, which may mean altering his/her daily plans to meet the agenda of a patient or family, because the nurse never knows what he/she may encounter when they enter the home of the terminally ill. "I'd rather be in the moment and get into trouble a little bit because I give all of what I have and all of what I am for the moment for each of my patients."

Being in the moment requires focus and concentration on the part of the hospice nurse and being content to be with the patient instead of doing for the patient. Hospice nurses see tremendous value in just being with someone who is dying and "really hearing what's going on, instead of always thinking about what you've got to do next and not really paying that much attention." One nurse described being in the moment in the following way:

I'm in the moment and I get into a lot of trouble for that, because where I am is where I am. I am late for

some things until I suddenly go, "Whoops! I've got to get out of this moment and get into the next one." But in that moment where I am, people have me 100%. I'm yours right now and what you need from me, if I've got it, you'll get it. If you're not in the moment and you are with a patient, then you are not truly there for that patient.

Death is Not the Enemy

Hospice nurses believe and practice a commitment to quality of life, not quantity of life and accept the fact that everyone will die. They also separate the idea of death from dying. Death is the terminal event that brings this life to an end. Hospice nurses believe that "death is as much a part of life, as life is a part of life."

"[Death] is the ornament of life, the thing that makes life what it is. It is the experience of death that makes us experience life."

Dying is a process that the patient and hospice nurse can have some control over. Hospice nurses do not intervene in the event of a death, but do intervene in the process of dying to ensure comfort care throughout the process. One of the goals in hospice care is for the nurse to help the patient to accept death and to see that death is not the enemy. "I just see death as a natural part of the life cycle. I don't see it as something to be internalized as

the enemy and something to be avoided at all costs." In accepting that death will occur and that all of their patients will die, hospice nurses do not accept responsibility or blame for the terminal illness.

I do not accept responsibility or guilt of any nature for the fact that this has happened. I am not God, I am not Buddha, I am not the doctor that has the answers to treatments, nor the researcher who has the answer to possible cures in the future....I just accept that this is the situation and work with it.

In order to cope with death on a daily basis, hospice nurses must acknowledge and recognize that the work is about their families and not about themselves and learn not to take each death personally. Hospice nurses know that they are not causing their patient's death, "but they are just there and part of the process." Hospice nurses know that death is inevitable. They also realize that their patients are going to die "whether I'm there or not and if I can make their death a little more meaningful, a little more comfortable and give them the chance and the opportunity to finish their work, then I have done my job."

Death can be a welcomed event when the journey of dying has been long and rough. One nurse described it this way:

There is almost a sense of jubilation and relief very frequently when the experience is over because we are

so happy for the patient, that they've been able to make this transition into another world and that they are no longer suffering....There is a real sense of wanting it to be over, and when it is over there is a real sense of closure that this thing is done and they've gone on to another life, another experience. So, rather than sadness, there can be joy and even gladness that the experience is over for the family and the patient.

Another way that hospice nurses cope with death is to recognize that as patients get closer to dying they begin to withdraw and disengage from the world around them, and that as this is occurring, the families begin to need more support from the nurse. One nurse stated that "most of my hospice relationships have been with the families and they continue to live, so it's really not totally about loss."

A Greater Awareness

For these hospice nurses their own spirituality and the spiritual experiences of their patients affected the way they lived their lives and the way they actualized their hospice nursing practice. Hospice nurses in this study reported a high degree of spirituality both in their personal lives and in their hospice practice. They stated that the spiritual nature of this work nurtured their own souls and beliefs, and kept them doing "His" work. Beliefs

in a higher or eternal significance to the work may account for the high purpose-in-life scores found by Amenta among hospice nurses generally (1984, 1996).

Hospice nurses expressed a keen awareness of a dimension or a place beyond this world and described situations that transcended temporal explanations. This "greater awareness" helped these hospice nurses to understand their place in this world and the importance of their work. One nurse described a "higher level of consciousness" that provided her with special experiences which gave her strength and provided insight into the needs of her patients.

Some nurses described this greater awareness as a "sixth sense" or "intuition" to be somewhere, to say something, or do something that they knew would offer patients and family comfort. One nurse depicted this greater awareness in the following way:

Sometimes it is just out of the blue. I was at a conference for two days and I was exhausted. It was a left turn towards home and instead I took the long way home and went past a patient's home and thought, "Well I might as well stop." And when I stopped, I knocked on the door and he was drawing his last breath, and you know, his mom and dad really needed to have somebody there right at that moment. They just needed somebody

there to support them. And you know, that happens a lot....You've got to believe in God and divine intervention; there have just been too many funny coincidences, that I know somebody's watching over us.

Hospice nurses were also open minded to the belief system of others. They respected their patients' religious practices, or whatever helped them to cope, and were careful not to push their beliefs onto others.

If I look at the earth around me, and I see the messages, wonderful things written in the Bible about God, and in the Torah and in the Muslim [book], and the Buddhist writings, nobody can screw up the message that a God is out there. All our needs are here they're provided for. Somebody really loves us and wants us to grow and learn...and death is part of this.

Beings from beyond. All of the nurses interviewed for this study believed in a higher being or force that guides their lives and loves them, whether they practiced an organized religion or considered themselves to be spiritual. Informants described beings from beyond using words such as "God", "angels", "spirits", or "deceased relatives of their dying patients." These nurses related stories of near death experiences or dreams heard from their patients that served as a reaffirmation of their own belief system and gave an eternal perspective and meaning to the work that they do.

These dreams and experiences gave comfort to the patients, families, and nurses, and through these spiritual experiences everyone involved learned that death is not the enemy. One nurse describes how knowledge of "comforting or guardian angels" provides support for everyone involved in the dying process and lessens their fear of death:

The interesting thing is that people share the same experiences with me whether they believe in an after-life or they don't, whether they are practicing a religion or not; they seem to have the same experiences...of seeing relatives that have died before or having dreams about people guiding them, and then they are no longer scared or afraid to die.

Hospice nurses admit that they cannot take credit for everything they do and say with patients, and acknowledge that they are "tools" or "instruments" for God's work.

I know that it's not me. I know that some of these people that I come across, that I just have this overwhelming love for, are not what I would call loveable if it was just up to me. That doesn't come from me. He does the work; I'm just the channel.

The nurses in this study feel that hospice nursing is important and sacred work. Hospice nurses believe divine interventions and spiritual experiences occur for their benefit and serve the purpose of reaffirming that there is a

God and angels intervening on their behalf to validate that this is the work that they need to be doing. One nurse stated:

It was a beautiful peaceful death at the end. One of the daughters said, and she had no reason to say this, because she didn't know that for the last couple of months I had been doubting. It was just really stressful being in the office, not being able to do this kind of being at the bedside, being in the moment. She said, "If you ever had any doubts where you were supposed to be or what you were supposed be doing, don't. You said everything I needed to say to him, to have him feel safe and to know that [it would be] OK." I was just frozen and silent.

Life after death. Of the nurses interviewed in this study all believed in life after death. The hospice nurses didn't "think of this life as being the terminus of all experience" and therefore did not personally fear death. These hospice nurses see death not as the end, but as a transition into another place that cannot be seen. One nurse described her belief in life after death in the following way:

My beliefs are what keep me in hospice. I don't think I could do hospice if I didn't believe in life after death. I mean that's a big part of what I practice. I

just believe that life continues so I think if I thought that this was the end of their life it would be pretty hard for me to keep doing it over and over.

Another nurse described "death as a re-birth into the next world, and therefore the patient's energy, life force, or soul, that thing that makes them what they are, continues and goes on to have other experiences." For these hospice nurses, this belief in an after life, an actual place where the soul goes after leaving this world, gives eternal significance to death, the dying experience, and the role that the nurses play during this transition from one existence into the next.

Divine Intervention

Hospice work can be difficult work. Within the context of doing hospice and working with the terminally ill, hospice nurses report that "something happens," or "something is done," or "something is said" that defies earthly explanations. These incidents are described by the hospice nurses as "divine interventions."

I know there's a million things I say and do that just affect people's lives, and it's God coming through my mouth, or the Holy Spirit, or whatever, just saying what He needed to say and reminding people...there is a God and He loves us all.

These divine interventions happen both for the benefit

of the patient and family, as well as the nurse. Hospice nurses believe that these occurrences happen in order to give people faith and hope, to help to expedite the journey of dying, or to let the living know that everything is alright and that the patient is no longer suffering. They also believe that divine interventions occur within the context of hospice in order to validate the importance and sacredness of this work.

One nurse described a traumatic incident in which she removed a comatose patient from a respirator at home. The hospice nurse thought she would be alone at the time, but for no apparent reason the social worker and an LVN showed up at the home.

The LVN got on the bed with [the patient] and laid down next to her and just held her head and talked to her as I turned off the respirator. Her breathing got labored and she was turning a dusky blue. Suddenly she woke up and was looking at me with fear and terror in her eyes and I was shaking so badly. Thank God that LVN just laid with her and said "Mary, it's okay" and coached her. I looked at the LVN and I wanted to bag [artificially ventilate] her. The LVN just said "No." We both knew what the patient's wishes were. Eventually...the patient settled down and finally stopped breathing. Thank God the LVN was there.

This hospice nurse believed that the social worker and the LVN "just showing up" was a divine intervention, and that their presence occurred to give her the strength to support the patient during this traumatic transition. This hospice nurse went on to explain:

I did not go back to work. I took the rest of the day off and I spent the whole day meditating and crying. It took me about one hour for me to finally invite this patient back into my consciousness and find out what happened, and she did finally appear to me. I finally let her come back, and she was beautiful. She had flowers in her hair and it was flowing. She just nodded her head like, "It's OK." Whether or not that experience was generated by my own mind or whether it was some other entity that came is not important. What's important is that I had this spiritual experience to basically process though this really traumatic experience. I think all [hospice nurses] have stories like this. That is why I think this kind of nursing is extremely profound.

Life Preparation

Hospice nurses believe they were being prepared for working in hospice and with the terminally ill throughout their lifetime. These nurses believe that through personal formative life experiences and previous experiences with

death and dying they come to their hospice vocation equipped to do the work of taking care of the dying and their families.

Equipped for Hospice

These hospice nurses believe that they come to the job of hospice prepared to do the work. Because of life experiences they bring talents and wisdom, as well as an ability to relate to patients that allows them to do the work of hospice.

I think I have come equipped to do [hospice] because I have always just felt really close to God. I've always felt the presence of God in the world around us, and this provides hope....They say He picks the lousiest instruments to do His work. I guess He couldn't find anybody worse off than me to do this job!

Life experiences prior to involvement with hospice, as well as hospice experiences with the dying, helped these nurses to be enlightened to the importance of working with the dying, and to grow spiritually, professionally, and personally. These formative experiences helped the nurses to be sensitized to the needs of those affected by death, to prioritize important aspects of life, and assisted them in achieving their work potential in a practice environment that these nurses report as extremely satisfying. One nurse described it this way:

My value system goes back to when I was a little kid, and I used to think about what I would do when I would grow up. I was sure that I would get married and have a family, but I was sure that this was the minimum expectation that God expected of me. That was the baseline. Somehow or other [I knew] there must be some other things that I needed to do in life to have made a difference, to fulfill my destiny, and I feel very fulfilled doing hospice nursing.

Discovering Death

Experiences with death and dying prior to involvement in hospice may also be a factor that helped to prepare these nurses for working with the terminally ill. These nurses reported an interest in death and the process of dying, because of personal experiences. One nurse described her feelings about growing up behind a graveyard.

I just always had this positive thing about people who died and their spirits, about Christ and the resurrection of spirits, and how guardian angels move among us. Once I had an experience where I knew someone was watching over me....I have felt a presence in a patient's room after they have died. I think it just kind of goes with who I am, and maybe that's why I get to do hospice. You know, maybe God has been preparing me to do this all my life.

Experiences with personal deaths prior to hospice nursing, either multiple deaths in their personal life of family members, friends, or special patients, or the experience of death at a young age, may assist these nurses to be prepared to do the work of hospice and operate from an empathetic perspective. These experiences with death had a profound effect on the lives of the nurses and influenced their career paths and life choices. "Looking back over my life, it's real obvious to me, I had a lot of deaths at a very young age." Hospice nurses in this study reported entering the profession of hospice nursing inspired by unique life experiences that can be equated to McDonnell's and Ferrell's (1992) critical incidents, which represent major influences throughout the life of a hospice nurse, which served to inspire or motivate them to move into this specialty area. One nurse described her experience with multiple deaths in the following way:

I had seven deaths between the time I was eighteen and twenty one. My god-child, my grandmother, my best friend in college...my best friend in eighth grade was killed on a horse; the night before graduation my boyfriend's friend was shot at McDonald's; a very dear friend got a brain tumor and died; my best friend in college was killed in a car accident; and then a very dear friend of mine...her baby got leukemia and died.

So I had a lot of deaths and that changed my whole life incredibly. I didn't think so then, but now I do.

The Hospice Vocation

These hospice nurses feel very close and committed to their work with the dying. Through life experiences with death and a strong sense of spirituality, hospice nurses come to their work equipped to work with dying patients; some hospice nurses feel that they have been "selected" to do this work. Hospice nurses feel that working with the dying is sacred work, a vocation, and a chosen profession.

I am probably not the most religious person in the world, but in a sense, I feel that [hospice] is a chosen profession; that this is as close to some of the kinds of things that you might hear in church about walking the walk and talking the talk. It is almost like a mission. You do this because you strongly feel that there is a need for this, and you know yourself that everybody might not feel the same, but those of us that do feel this way have a calling to do that, almost a calling I would say.

Life Perspectives and Values

A hospice nurse's unique life perspectives come from the lessons learned from the dying. This learned experience includes the following lessons: (a) simplicity, (b) quality of life, (c) fragility of life, (d) importance of

relationships, (e) order in life, and (f) death is the great equalizer. Hospice nurses stated that working with the terminally ill helps them to keep focused on the important values and aspects in life.

The Learned Experience

These hospice nurses learned many lessons from working with dying patients and their families. These lessons were learned in the context of the hospice nurse-patient or hospice nurse-family relationships which are described by the hospice nurses as "intimate", "sacred", and "privileged." The hospice nurses value these relationships and explained that they gain wisdom from their patients and families. They reported that these lessons came directly from their patients and families because they "give more than they ever take." The lessons and relationships can profoundly change the life perspective of a hospice nurse by helping him/her to keep focused on the important things in life. "Hospice is just a constant growing, a constant learning, a constant reaffirming of what I'm here for, what I'm doing, and what's important for my life."

Simplicity. The hospice nurses in this study believed that the most important things in life are not material possessions. "I've always been a relatively simple person, in the sense that I don't have a high need for material things. This whole hospice philosophy of palliative care

and really focusing on comfort and quality of life just fits for me." Hospice nurses assist patients with life review and often hear comments such as these from patients, "Oh well, it's really nice that I have this 6,000 square foot home, but I notice that there is no one here."

Quality of life. These hospice nurses value quality of life, not only for their patients, but also in their own lives. They describe themselves as being "introspective in exploring [their] personal life and the kinds of things that [they] would like to do for the quality of [their] own life."

Fragility of life. Through their work, these hospice nurses have come to recognize the fragility and uncertainty of life and that "any one of us could possibly become a hospice patient in the near future." They are not morbid and don't dwell on death, but realize that "it's a fine line sometimes between planning for a realistic future, which we all need to plan for, and realizing that we need to smell the roses along the way." Working with the dying helps the hospice nurse to learn "not to sweat the small stuff in life....For me, it's really defined what is important and what isn't, what I want my life to be about, and that is relationships and experiences, rather than 'stuff'."

I have gained a lot of wisdom that I didn't have before. [Hospice] has made me accept changes in myself

and in my relationships. It affects everything I do....I used to think I wanted to have a big house and do all the things everybody else does, but I just kind of went, "You know, what I really want to do is ride a horse. If I buy a house I won't be able to ride my horse. "So I have a horse and I'm not going to be able to do that forever. I could get hit by a car, or get cancer, or die tomorrow. So do the things you want to.

Importance of relationships. Hospice nurses value family life and relationships. They believe that life is given value, not through material possessions but through relationships, and recognize the importance of simplicity in a life unencumbered by the trappings of wealth. Hospice nurses value relationships, because they feel that they have value, are enduring, and are sustaining to those involved. Hospice nurses value relationships in their personal and professional lives that nurture and support the nurse as a caregiver and human being. This value in relationships with other hospice team members, may be related to Bram and Katz's (1989) findings that hospice nurses "perceived greater opportunity to express work related feelings and to discuss problems in the work place" (p. 558). This value of relationships is also substantiated by these hospice nurses in the importance they placed on the lasting ties formed with the families of their deceased patients.

Order in life. As a group hospice nurses recognize the need for balance and order in their personal life. One informant described order in life in the following way:

I don't think you can continue to do hospice nursing unless you have order in your life. My observation is, it becomes very difficult to do a good job of focusing on a [hospice] family's needs when you are having a personal crisis of your own. I also think that balance in your life is extremely important when you're in a hospice nursing situation. You need to be in a position where you are being nurtured yourself at some level, where either you've picked out some activities for yourself...or your family is supporting you in that way. I really firmly believe that we need support systems, balance, and order in our personal life to continue to do this kind of nursing.

Hospice nurses believe in being prepared for death, but not just physically and spiritually. "The first year or so after I became a hospice nurse I wrote my Durable Power of Attorney and my will." Hospice nurses reported as a group the importance of getting their own life in order because they witness the "turmoil and confusion that occurs for loved ones if certain kinds of things haven't been done."

Hospice nursing forces you into dealing with some deep life issues of your own....You can't get away from it.

It's something we all have to do, and we all kind of live in denial in our life without [thinking] what it's really about and why we're here. Being exposed to people in that place in their life gives you some glimpses into it to prepare and to live a better life yourself. To really value your life.

Death is the great equalizer. Hospice nurses believe that in death we are equal and that death knows no racial, economic, social, or political boundaries. "When someone dies they're pretty much equal at that point, and [hospice] has really showed [sic] me who I want to be and where I want to be when I am facing that point in my life." Hospice nurses believe that it doesn't matter how much money you have, where you live, or what your belief system is, there is value to life and equality for everyone in death.

Death is the great equalizer. So then you can see across the board and ponder: What is it really that my lady in Los Gatos that's a millionaire wished she had done more with in her life and wished that she had gotten out of her life? And what is it that my poor woman from Iran is wanting and wishing that she had? Across the board you can see it from every nationality and every economic level, people wished that they had spent more time in relationships, and people wished they had not been so uptight about so many things.

Chapter 5

DISCUSSION

Summary of Study

This study examined what motivates or influences nurses to become hospice nurses and sought to describe their lived experience. Registered nurses currently working as hospice nurses were recruited on a volunteer basis, purposeful sampling resulted in the selection of five study participants. After informed consent was given, each nurse was interviewed with the help of a semi-structured interview guide developed by the researcher. The researcher used the phenomenological technique of bracketing in preparing for and carrying out the interview process. The researcher used insight, reflection, sensitivity, and intuition during the analysis phase to search for common themes among the interviews. Thirteen primary themes evolved from the interviews which included: The Death Taboo, Team Spirit, Holistic Care, The Inhospitable Hospital, Dual Autonomy, Making a Difference, Death is Not the Enemy, A Greater Awareness, Divine Intervention, Equipped for Hospice, Discovering Death, The Hospice Vocation, and The Learned Experience. Fifteen secondary themes also began to emerge which were distinct, but could be grouped under main themes and served to organize ideas along similar thematic lines. These secondary themes were: Importance of Psychosocial,

Importance of Spirituality, Patient Autonomy, Nursing Autonomy, Enabling and Empowering, Being with the Dying, Being in the Moment, Beings From Beyond, Life After Death, Simplicity, Quality of Life, Fragility of Life, Importance of Relationships, Order in Life, and Death is the Great Equalizer.

The composite view of hospice nursing as conveyed by these nurses is described here. This synthesis of themes and ideas represents the thoughts and experiences of the five nurse informants who participated in this study, rather than hospice nurses in general and is an initial attempt to capture the phenomenon of the lived experience of the hospice nurse.

These hospice nurses believe that the essence of their work lies in making a difference in the lives of dying patients and their families through reframing, empowering and enabling. They reframe the death and dying situation, which serves to move the focus of care away from the disease process and the technology of dying, back to the patient as a spiritual and feeling human being. These are the things that they perceive as making hospice nursing distinct from other ways of dealing with the terminally ill and without which it would not be a unique practice. This definition supports the definition of essence and specialization found in McDonnell and Ferrell (1992).

This group of nurses believe that "being there" for the dying patient and their family is a special aspect of hospice nursing. However they go beyond the concept of being there as described by Haberman et al. (1994) and Cohen and Sarter (1992) into "being with the dying" and "being in the moment." Hospice nurses role model being with the dying for other professionals and families, and describe this aspect of their job as extremely nurturing to their souls and a part of their job that they cherish and value. Hospice nurses believe that "being with the dying" and "being in the moment" are integral concepts that support the terminally ill through the process of dying. They value the psychosocial and spiritual aspect of hospice which gives them satisfaction, helps to reaffirm their own beliefs in an afterlife, and provides hope and comfort to the terminally ill.

Hospice nurses are a distinct group of nurses that have unique life experiences, perspectives, and values that have prepared them to do work with dying patients and their families. Hospice nurses come equipped to do hospice work through a heightened exposure to death and dying, a calling from God, or choosing the profession because it is the right thing for them to do and, they feel prepared to do it. Hospice nurses leave the hospital environment where there is inadequate support for professional autonomy and the

psychosocial/spiritual aspects of nursing care, and they find these elements supported and even encouraged within hospice. Hospice nurses display a passion and dedication for their work similar to the findings on intrinsic motivation of Amabile et al. (1994).

Hospice nurses value relationships, not material possessions, and accept that in death people are all equal. Hospice nurses do not feel that death is the enemy, and recognize that death can even be a welcomed event. Hospice nurses value quality of life, not quantity of life, for both themselves and their patients, acknowledge that life is very fragile, and realize that at any moment any one of us could be a hospice patient. They value the team concept of hospice and dual autonomy for themselves and the patient. Hospice nurses encounter a taboo surrounding their work with death and dying. Hospice nurses learn many lessons from the terminally ill and admit that they gain much more than they ever give to their patients. Hospice work helps the hospice nurse to keep focused on what is truly important in life.

Conclusion

Hospice nurses are able to describe the essence of what they do, which is to make a difference in the life of the terminally ill through enabling, empowering, and reframing. It is this essence, combined with support for personal beliefs and professional values that motivates and

influences nurses to choose this unique specialty.

Hospice nurses have learned to define their care based on the wishes of their dying patients and their families, rather than needs dictated by the medical community. A hospice nurse meets his/her patients where they are and assists them in dealing with whatever life and death has in store for them, as they embark on this lifetime's final journey together. Hospice nurses face death on a daily basis and have learned to find rewards in this special kind of nursing that are distinct from the values of their colleagues in acute settings who are focused on "curing" the disease. Acute care nurses attempt to affect "quantity of life;" hospice nurses focus on "quality of life," no matter how short the time may be.

Hospice nurses have a spiritual perspective and understanding in their professional work with the dying and in their personal lives. The hospice nurses in this study acknowledged their belief in the presence of a higher being and the occurrence of divine interventions. These special experiences, coupled with the administrative support and time to facilitate the psychosocial and spiritual nature of hospice work are consistent with the lower burnout scores for hospice nurses as reported by Bram and Katz (1989).

Hospice nurses have an intense desire to work with the terminally ill in spite of a lack of acknowledgement from

other professionals. Hospice nurses believe that hospice nursing is special with its own unique set of skills and knowledge that helps to set this type of nursing apart from other ways of treating the terminally ill. Hospice nurses are a unique set of caregiving professionals who have experienced distinctive life situations which have had a profound impact on their nursing career and have led to this career choice. The Holy Bible (1983) states, "Each one should use whatever gift he has received to serve others, faithfully administering God's grace in its various forms" (1 Peter, Chapter 4, Verse 10, p. 1549). The hospice nurses in this study believe that through formative life experiences and special talents they have been prepared throughout their lifetime to do the work of hospice, which they consider to be sacred and privileged work.

Scope and Limitations

The sample size in this study was small and it is understood that the statements of these nurses do not represent all hospice nurses' views. The participants in this study were purposively selected by the researcher which also may be a limitation of this study. A larger sample size, including nurses from a broader hospice population, from additional settings, or cultures would need to be conducted in order to allow for the findings of this research to be generalized to all hospice nurses. This

researcher acknowledges that the themes in this study representing the lived experience of the hospice nurse are not exhaustive. Other themes or categories may be identified through future research.

The findings of this research also are specific to this study population, hospice nurses who work in a community based hospice, and are not generalizable to other types of nurses, other types of hospice workers, or other types of nurses who work with the terminally ill in other settings.

Another limitation of the study was that all of the nurses interviewed were female and their statements may not reflect the feelings of males who work with the terminally ill. However no males volunteered for the study which may reflect that men are under-represented in the female dominated profession of nursing, that there are a lack of men working in hospice, or that male hospice nurses were not interested in volunteering for this research.

Another anticipated limitation to this research was that all of the volunteers were acquaintances of the researcher. The researcher is known within the local hospice community and this "familiarity" could not be controlled for. This may have contributed to the open display of emotions, talkative nature, and willingness of the participants to share their thoughts. Furthermore, some aspects of the hospice lived experience may not have been

recorded or revealed since some level of knowledge of the work of hospice may have been perceived to be understood as common knowledge by the study participants.

Recommendations for Future Research

Hospices can be community based or hospital based. A comparative study looking at these two different types of hospice nurses would be an interesting future direction for this research. In addition, hospices employ paid and volunteer staff members with varying levels of education and training who comprise their interdisciplinary teams. These teams consist of, but are not limited to: Registered nurses, licensed vocational nurses, home health aides, social workers, volunteers, chaplains, and physicians. Since all members of the hospice interdisciplinary team chose to work with the terminally ill and enter this type of work knowing that their patients will die while under their care, future research could explore whether the findings of this research are similar to the experiences of other members of the team.

An attempt to control for familiarity and potential bias should be made by carrying out a similar study of subjects who are not known to the researcher. Another future direction for this kind of research would be to explore the lived experience of male hospice nurses to identify new themes that may occur because of gender

differences.

It was a surprising finding of this researcher to discover that none of the nurses in this study had pursued individual memberships in professional associations and organizations for hospice nurses. Furthermore, only two of the five hospice nurses in this study had sought formal recognition and certification within their specialty area. It would be an interesting future study to determine if this lack of certification and membership within the specialty of hospice is related to a lack of recruitment by the National Hospice Organization, or whether it reflects the hospice nurses' intrinsic motivation for this work.

This study provided a beginning attempt to ascertain and convey the lived experience of community hospice nurses, and thereby it provides an important knowledge base for future studies of hospice nursing.

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APPENDIX A

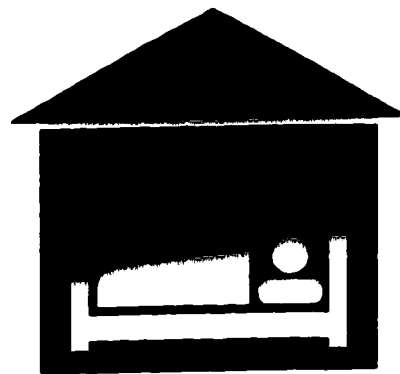
Flyer

WANTED



HOSPICE NURSES

TO PARTICIPATE
IN
NURSING RESEARCH STUDY



For more information call
Terri @ (408) 226-1622

APPENDIX B
Phone Data Collection Tool

PHONE DATA COLLECTION TOOL

Demographic Information

Name:	
Address:	Phone Number:
Gender: <input type="checkbox"/> Male <input type="checkbox"/> Female	Age:

Employment & Educational Information

<u>Level of Education</u> <input type="checkbox"/> Diploma Nursing Program <input type="checkbox"/> ADN <input type="checkbox"/> BSN <input type="checkbox"/> MSN <input type="checkbox"/> CNS <input type="checkbox"/> NP <input type="checkbox"/> Doctorate <input type="checkbox"/> Other: _____	<u>Specialty Certification</u> <input type="checkbox"/> Yes <input type="checkbox"/> No Specify: _____ <input type="checkbox"/> PHN
Professional Affiliations: _____	
<u>Professional Experience</u> Number of Years of Work Experience in Nursing: _____ Number of Years of work Experience in Hospice: _____	

What made you decide to call me? _____

APPENDIX C
Informed Consent

College of Applied Sciences and Arts • School of Nursing
One Washington Square • San Jose, California 95192-0057 • 408/924-3130 • Fax 408/924-3135

**AGREEMENT TO PARTICIPATE IN RESEARCH
AT SAN JOSE STATE UNIVERSITY**

RESPONSIBLE INVESTIGATOR: Teresa Ann Simpson, R.N., B.S.N.

TITLE OF PROTOCOL: What Motivates or Influences Nurses to Become Hospice Nurses?

PURPOSE OF STUDY: I have been asked to participate in a nursing research study to determine what motivates or influences nurses to become hospice nurses. I am being asked to participate in this study because I am presently employed as a hospice nurse.

PROCEDURES:

If I agree to be in the study, I understand that the following will occur:

1. I will be interviewed by the researcher for approximately 1 to 1½ hours. This interview will be tape recorded so that no information I give will be omitted.
2. My identity and the identity of the agency where I am employed will be kept confidential. Numbers, rather than names, will be used for storing, transcribing and analyzing the tapes. Audiotapes and demographic information will be kept in a locked box at the researcher's home. Audiotapes will be erased after the interview has been transcribed. Information that could identify study participants will be destroyed after the study has been completed.
3. The interview will be held in a mutually agreed upon location, away from the homes or places of employment of either myself or the researcher. The interview will occur on my own time.
4. The researcher will contact me by phone to request a follow-up meeting once the interview has been analyzed. The purpose will be to determine if the researcher's composite analysis of the interview fits with what I stated and captures the true meaning of hospice nursing for me.

RISKS/DISCOMFORTS:

1. I may feel discomfort or embarrassment with being interviewed or tape recorded.
2. I may feel a range of emotions at remembering and sharing specific patient care experiences or encounters. If I feel uncomfortable with any of the questions I can choose not to answer.
3. There are no other reasonably foreseeable risks or discomforts to the subjects participating in this study.

Initials of Study Participant

POSSIBLE BENEFITS:

1. I may feel a range of emotions at remembering and sharing specific patient care experiences.
2. No tangible benefits are provided as a result of this study, however, the positive effect of participating in research to potentially help others or benefit nursing in general could possibly be viewed as a benefit.

COSTS:

Neither I nor my institution will be compensated for participation in this study, however, depending on the location of my interview, the researcher will pay for any food or beverage served while I am being interviewed. There is no cost to participants in this study.

DISCLOSURE:

1. The results of this study may be published or presented at scientific meetings. Any information from this study that can be identified with me will remain confidential and will be disclosed only with my permission, or as required by law.
2. No service of any kind, to which a subject is otherwise entitled, will be lost or jeopardized if I choose to "not participate" in this study.

QUESTIONS:

Any questions about the research may be addressed to the principal investigator, Teresa Ann Simpson, R.N. at (408) 226-1622. Complaints about the research may be presented to the graduate coordinator, Coleen Saylor, R.N., Ph.D., at (408) 924-1321, or the Department Chair, Bobbye Gorenberg, R.N., D.N.Sc., at (408) 924-3130. Questions or complaints about research, subjects' rights, or research related injury may be presented to Serena Stanford, Ph.D., Associate Academic Vice President for Graduate Studies and Research, at (408) 924-2480.

CONSENT:

My consent is given voluntarily without being coerced. I may refuse to participate in this study or any part of this study, and I may withdraw at any time, without prejudice to my relations with my place of employment or San Jose State University.

I have received a signed and dated copy of this agreement.

Signature of Study Participant

Date

MY SIGNATURE INDICATES THAT I HAVE READ THE ABOVE INFORMATION AND THAT I HAVE DECIDED TO PARTICIPATE IN THE STUDY.

Signature of Investigator

Date

THE RESEARCHER'S SIGNATURE ABOVE INDICATES AGREEMENT TO INCLUDE THE ABOVE PERSON AS A SUBJECT IN THE STUDY AND ATTESTATION THAT THE SUBJECT HAS BEEN FULLY INFORMED OF HIS/HER RIGHTS.

APPENDIX D

Human Subjects Approval Letter



San José State
UNIVERSITY

Office of the Academic
Vice President

Associate Vice President
Graduate Studies and Research

One Washington Square
San Jose, CA 95192-0025
Voice: 408-924-2480
Fax: 408-924-2477
E-mail: gstudres@wanoo.sjsu.edu
http://www.sjsu.edu

TO: Teresa Ann Simpson
5215 Barron Park Drive
San Jose, CA 95136

FROM: Serena W. Stanford *Serena W. Stanford*
AAVP, Graduate Studies & Research

DATE: April 4, 1997

The Human Subjects-Institutional Review Board has approved your request to use human subjects in the study entitled:

"What Motivates or Influences Nurses
to Become Hospice Nurses"

This approval is contingent upon the subjects participating in your research project being appropriately protected from risk. This includes the protection of the anonymity of the subjects' identity when they participate in your research project, and with regard to any and all data that may be collected from the subjects. The Board's approval includes continued monitoring of your research by the Board to assure that the subjects are being adequately and properly protected from such risks. If at any time a subject becomes injured or complains of injury, you must notify Serena Stanford, Ph.D., immediately. Injury includes but is not limited to bodily harm, psychological trauma and release of potentially damaging personal information.

Please also be advised that all subjects need to be fully informed and aware that their participation in your research project is voluntary, and that he or she may withdraw from the project at any time. Further, a subject's participation, refusal to participate, or withdrawal will not affect any services the subject is receiving or will receive at the institution in which the research is being conducted.

If you have any questions, please contact me at (408) 924-2480.

The California State University:
Chancellor's Office
Sacramento, Chico, Dominguez Hills,
Fresno, Fullerton, Hayward, Humboldt,
Long Beach, Los Angeles, Maritime Academy,
Monterey Bay, Northridge, Pomona,
Sacramento, San Bernardino, San Diego,
San Francisco, San Jose, San Luis Obispo,
San Marcos, Sonoma, Stanislaus

APPENDIX E

Semi-structured Interview Guide

SEMI-STRUCTURED INTERVIEW GUIDE

Instructions: ***Please answer the following questions in your own words. There are no right or wrong answers. Take as much time as you need and answer each question as openly and honestly as you can.***

1. When did you decide to become a nurse and why did you chose nursing?
2. How was it that you ended up in hospice?
3. How would you compare hospice nursing with other kinds of nursing that you have practiced in the past?
4. What makes hospice nursing special?
5. How do you think your beliefs or values have influenced your style or work with your hospice patients?
6. What is it about hospice nursing that you value?
7. Describe an incident in your hospice experience that reflects the essence of what you do as a hospice nurse.
8. What has hospice nursing meant to you in your own personal life?
9. What gives you a sense of fulfillment in your work?
10. If someone were to say to you: "Well, how can you stand it, knowing that all your patients are going to die?" What would you say?
11. How has hospice nursing affected your own view or perspective of life & death?
12. Is there anything else about what you do, that you think I should know?